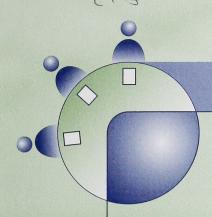
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2004 Community Disability Forum Summary Report





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• Please note: These presentations and comments were extracted directly from the Symposium transcript. The transcript was produced from real time captioning and not an audiotape. It is not certified therefore as a verbatim record. This material has not been edited for content, grammar or syntax.



Introduction

In February 2004, Alberta Community Development Minister Gene Zwozdesky announced the creation of the Office for Disability Issues (ODI). The advent of ODI signified a firm commitment on behalf of government to action recommendations contained within the *Alberta Disability Strategy*, which was released by the Premier's Council on the Status of Persons with Disabilities in December 2002.

The new ODI will provide a central reference point for matters affecting persons with disabilities and facilitate the development of government policies that remove barriers and create more accessible programs and services. Community involvement and support is important to the success of ODI, as it will work with stakeholders both inside and outside government to resolve disability issues.

ODI staff recognized the need to bring together leaders from disability community organizations and ask for their counsel and guidance before developing plans for the future. The Premier's Council facilitated this by inviting 46 provincial organizations to send two representatives to a one and a half day meeting in Red Deer June 17 and 18, 2004. In addition to community expectations of ODI, participants were asked to bring their thoughts and suggestions regarding the future role of the Premier's Council.

This document summarizes the input provided by the 67 people who attended the Disability Community Symposium. The Symposium was the first of its kind and it was the opinion of the vast majority of those who attended that such gatherings should be held on a regular basis.

In addition to ASL interpreters, a real time captioner transcribed Symposium plenary sessions into text. The transcript, along with additional copies of this document, are available from the Premier's Council's office. This summary document is also available on-line at www.cd.gov.ab.ca/helping_albertans/premiers_council

Executive Summary

The focus of the first day of the Symposium was the Office for Disability Issues (ODI). In five small groups, participants were asked to consider and respond to three questions:

- 1. What are the community's expectations of ODI?
- 2. What are the challenges and issues associated with trying to meet these expectations?
- 3. What are the collaboration opportunities for ODI and community stakeholders?

Each small group reported back to the plenary. These reports are included in Section II of this document.

The second day of the Symposium focused on the future role of the Premier's Council. Comments by a panel of Premier's Council members (Chair Rob Lougheed and members Gordon Bullivant and Margaret Conquest) were followed by input from participants. The panel's comments are also contained in Section II.

Community Expectations of ODI

Community expectations of the Office for Disability Issues were varied and wideranging but communications was a central theme. Participants saw ODI playing a major role in communicating and raising awareness within government of disability issues and needs. At the same time, ODI should act as a liaison between government and community stakeholders. This liaison role should extend to housing up-to-date information on disability services and

resources, and helping individuals and organizations navigate through government departments and programs.

It was acknowledged that providing an information and referral service would require ODI to engage in research activities. Many participants encouraged ODI to conduct research that identified inefficiencies and duplication within disability programs and services.

ODI should be a conduit for the collective voice of the disability community to be heard in government, said participants. When appropriate, ODI should represent the interests of persons with disabilities by bringing issues forward to government departments and advocating for change.

There was consensus that ODI should be action orientated and have sufficient "clout" to influence government policies and programs. There was an expectation that ODI would bring more accountability to government programs and services, evaluating programs and helping to identify

service gaps and barriers. It was expected ODI would facilitate the closure of gaps or removal of barriers within or between government departments.

Transparency and accountability were important to participants. To ensure transparency and accountability, they recommended regular communications and dialogue with community stakeholders, and reports on government's progress in implementing the core recommendations of the *Alberta Disability Strategy*.

Challenges and Issues facing ODI

Meeting high community expectations with limited resources was seen as a significant challenge for ODI. Participants foresaw ODI being inundated with stakeholder requests, issues and needs, many of which may be inappropriate or unreasonable. Being a "dumping ground" for all things related to disability would hamper ODI's ability to focus on core issues like establishing a credible presence across government, advancing the *Alberta Disability Strategy* and being responsive to community organizations.

Credibility and influence within government was another major issue identified by participants. Many believed ODI's success was dependent on getting buy-in and acceptance from other ministries. Without it, ODI would have great difficulty facilitating change.

Participants felt that clearly defining and communicating ODI's role, protocols, processes and plans would help stakeholders understand ODI's mandate and intentions vis-à-vis disability issues. Bringing clarity to ODI's place in government and its priorities for the future would limit misunderstandings and false expectations both within and outside government.

Some participants said recognizing all disability groups equally and in a manner that was inclusive would be a challenge for ODI. Effective communication links with community groups was seen as a key to on-going awareness and sensitivity regarding a myriad of issues and needs.

Some participants suggested there are individuals and groups (e.g. Hutterites, Aboriginals) that are either afraid to approach ODI or would consider ODI "not to be for them". They indicated ODI needed to address these attitudes in its communication and outreach efforts. Respecting and dealing with federal/provincial jurisdictional obligations concerning Aboriginals, without losing focus on their issues, was mentioned as a challenge for ODI.

Other issues for ODI cited by participants include:

- Lack of a common definition of terms for disability groups and communities.
- Inadequate demographic data regarding the disabled population.
- Establishing a services and issues focus.
- Achieving success or progress in a short time.
- Making connections to the non-disabled community.
- Turf protection within government departments.
- A possible backlash from those who prefer the status quo.
- Outreach to those who don't selfadvocate.

Collaboration Opportunities

For the most part, Symposium participants envisioned ODI would build partnerships with community organizations and private sector companies to resolve disability issues, to engage in joint advocacy, and to create or enhance communication links and information sharing.

There was consensus that strong links should be developed and maintained between ODI and disability community organizations. It was noted that the Symposium provided a good setting for gathering input from such organizations. Regular face-to-face forums of this nature should continue, said participants. Some participants favoured developing crossministerial or regional committees as an on-going input mechanism for ODI.

Other specific collaboration opportunities that were mentioned include:

- Involvement in disability awareness weeks.
- Partnering with other provincial, federal and international disability offices or organizations.
- Forming community advisory committees to work on specific issues.
- Working with disability groups to challenge communities to be inclusive.
- Capturing new consumers, clients or stakeholders for organizations through referrals.

Future Role of the Premier's Council

Participants expressed support for the Premier's Council and encouraged Council to continue as an advisor to government on disability issues. Some supported the Premier's Council acting in a formal capacity as an advisory board to ODI.

Although participants acknowledged that ODI would largely be responsible for implementing the *Alberta Disability Strategy*, it was felt that the Premier's Council should monitor ADS' progress to ensure recommendations were being acted upon. Several participants saw ensuring government accountability for policies and programs as a legitimate role for the Premier's Council.

Of most concern to participants was confusion regarding the role and functions of ODI and the Premier's Council. There was consensus that the Premier's Council should remain a public, objective, politically orientated organization that provides government with a community perspective on disability issues. ODI, on the other hand, was seen as an internal mechanism within government that is responsible for stimulating improvements in disability policies, programs and services.

The relationship between the Premier's Council and ODI was seen as being mutually supportive but participants felt it was important that there be a clear separation between the two. The Premier's Council should remain arms length from the bureaucracy so it can freely advocate for persons with disabilities among elected officials.

It was noted that sharing the same office and having the same Executive Director contributes to the confusion about organizational mandates. It was suggested that the Premier's Council define its relationship with ODI and government as a whole and communicate that information to its various publics. This presents an opportunity to raise the Premier's Council visibility and profile, which a number of participants mentioned is important if it is to remain in touch and connected with the needs and issues of persons with disabilities. It will also help the Premier's Council strengthen its relationship with disability communities, commented some participants.

The Premier's Council was encouraged to continue to play a role in educating government officials, the public and the media on disability issues. This education should include a clear articulation of what full inclusion in the community means and, subsequently, promoting communities to create inclusive environments.

Some participants called for the Premier's Council to add members that better reflected the broad diversity of the disability community. Specific suggestions included the addition of parents who have children with disabilities, individuals with a mental health, deaf blind or other specific disability not currently represented, and persons with disabilities who are also visible minorities. One participant called for a member of the Premier's Council to focus on addressing Aboriginal issues.

Representatives of the deaf and hard of hearing community called on the Premier's Council to conduct research into providing 24 hour, seven days a week interpretive services for the deaf and hard of hearing in Alberta. They explained that community inclusion for the deaf couldn't happen unless the communication barrier is overcome. They suggested a separate office, in addition to ODI, might be needed to ensure the needs of the deaf and hard of hearing are adequately met.

Small Group Discussions

Group Yellow Breakout Session

Community Expectations of ODI Priorities

- Ensure the community is present at the policy tables of government departments.
- Facilitate communication:
 - Between groups serving people with disabilities.
 - Take on a liaison role via a website that links individuals, agencies and resources.
 - Disperse up-to-date information.
 - Help people navigate through government – producing referrals to other areas of government.
- Build community capacity:
 - Respond to urgent issues as they arise.
 - Support what is currently in place and help develop new initiatives.
 - Encourage a focus on the provision of services based on an individual's need rather than type of disability.

Other Expectations

- Develop a strategy that addresses mental health and personal supports inadequacies.
- Incorporate mental health in personal supports.
- Develop an inventory of resources in the province. Use technology to collect and disseminate information.

- Advertise ODI's existence/role/services.
- Address provincial issues like transportation and inequality between regions. Take this information to the relevant ministry or department to effect change to policies.
- Mobilize government and community to address specific issues like housing, income, transportation and employment.
- Provide regional representation and input on housing issues.
- Address mandate issues that segment or prevent service delivery.
- Coordinate research conduct pilot projects, build relationships with research bodies, encourage participation in research.
- Highlight champions of good practice.

Challenges and Issues for ODI

- Clarifying the role of ODI (i.e. will it act as a ministry for disabilities?).
- Setting clear priorities that are communicated.
- Being transparent and accountable.
- Getting representation from across the province.
- Developing processes for communication.
- Getting 11 government departments to "buy-in".

- Providing equitable recognition of all disability groups.
- Meeting the high expectations of the community.
- Providing evidence of progress/success within a short period of time.
- Having significant impact with ODI's limited resources.
- Developing communication and using language that is inclusive of all disability groups.

Collaboration Opportunities for ODI and Community Organizations

- Regularly meeting face-to-face with stakeholders.
- Developing a regional structure of input and feedback.
- Leveraging existing networks and encouraging the development of new networks.
- Working with other disability groups to challenge communities to be inclusive.

Group Purple Breakout Session

Community Expectations of ODI Priorities

- Clarify jurisdiction and responsibility on complex disability issues that involve more than one government department.
- Influence policy and create bureaucratic links between various departments and policies.
- Promote, communicate and raise awareness of disability abilities & needs within government. Engage in advocacy.
- Operationalize the recommendations of the *Alberta Disability Strategy*.
- Develop authority and clout so that ODI has impact and the ability to effect change.
- Promote accountability. Establish benchmarks to determine how well government programs are doing with the customers (that is, persons with disabilities).

- Identify issues and services that need continuity, portability, equity and standards.
- Provide better coordination of the 11 departments and 32 programs with disability programs.
- Identify duplication and cost saving efficiencies.

Other expectations

- Provide information and referral services on disability issues.
- Be transparent, with regular communications to the community.
- Facilitate opportunities, networking and partnerships between community agencies.
- Work towards continuity, portability and equity of services across the province.
- Identify issues that need provincial standards.

Challenges and Issues for ODI

- More staff to prioritize issues.
- Establishing a services and issues focus rather than a disability specific focus.
- Resolving jurisdictional issues between levels of government (e.g. federal/provincial regarding First Nations).
- Overcoming inadequate demographic data on the disabled population.
- Meeting community expectations.

Collaboration Opportunities for ODI and Community Organizations

- Engage community advisory committees to work on specific issues.
- Build and improve community capacity.
- Hold an annual stakeholder conference.

Group Green Breakout Session

Community Expectations of ODI Priorities

ODI should have influence/impact at all three levels of government. Across these levels, ODI could engage in the following:

- Referrals making or facilitating connections for a variety of purposes.
- Information doing environmental scans; collecting and disseminating data, identifying what is working and what isn't; conducting or facilitating research into best practices.
- Advocacy bringing issues forward to agencies and ministries; acting as a catalyst for resolving issues (not necessarily resolving the issue directly).
- Policy development Review upon request the policies of community agencies; make recommendations on

disability issues to government policy makers at municipal and provincial levels.

- Evaluation evaluate programs and policy outcomes.
- Conflict resolution act as a mediator between a person and an agency; between an agency and government; between an agency and an agency; between a person and government.
- Be an over-arching organization or mechanism that interfaces between various stakeholders to identify, articulate and resolve specific or global disability issues.
- Provide a collective voice for the disability community.
- Provide a level playing field for all disability issues to be heard.

Other expectations

- · Be accountable.
- Educate MLAs, the bureaucracy, and the public regarding disability issues using a variety of tools like the World Wide Web and alternative communications.
- Identify service gaps placing some onus on agencies to bring gaps to ODI's attention.

Challenges and Issues for ODI

- Articulating ODI's core values and role.
- Providing a common definition of terms for disability groups and communities so they can speak a common language.
- Exercising wisdom, innovation, sensitivity and respect when engaging Aboriginal communities while being aware of federal/provincial jurisdictional obligations.
- · Allocating limited resources.
- Competing with other voices for change (i.e. other groups like the Premier's Council, Alberta Disabilities Forum, etc.)
- Establishing power, influence and credibility within government.

- Avoiding being a dumping ground for all things.
- Dealing with unreasonable expectations (i.e. responding to every individual issue).
- Doing adequate follow-up on actions taken

Collaboration Opportunities for ODI and Community Organizations

- Partner with the federal ODI.
- Facilitate partnerships with the private sector to resolve some disability issues.
- Get involved with disability awareness weeks.
- Create strong links with the Alberta
 Disabilities Forum and other disability
 groups.
- Establish cross-ministerial committees and develop mechanisms to gather regular input from government departments.
- Provide a regular forum to discuss crossdisability issues.
- Maintain a presence in the community and keep an open mind about collaboration opportunities.

Group Blue Breakout Session

Community Expectations of ODI Priorities

- Engage in communication and relationship building:
 - Provide awareness and education of accessibility standards (e.g. signage, parking, buildings, etc.) to various publics.
 - Be a conduit to government for input from Albertans with disabilities.
 - Help educate health regions re: mental health issues.
- Coordinate service provision:
 - Identify gaps and solutions at the program level and up.
 - Help individuals and agencies to navigate through the system.
 - Provide a user-friendly point of entry into government programs for individuals, groups and initiatives – avoid creating a bottleneck.
 - Promote the disability lens on government policy matters.
 - Provide a broad evaluation of disability programs and report the results to Albertans.
- Clarify ODI's mission and role.
- Support the implementation of the *Alberta Disability Strategy* by championing ADS within government and reporting on its progress to the community.
- Advocate on behalf of persons with disabilities to government ministries and programs.
- Overcome jurisdictional disputes in the provision of services to Aboriginal Albertans with disabilities.

Other expectations

- Explore best practices in other jurisdictions.
- Help seek out supports for family and other caregivers.
- Seek ways to pool resources within government and develop cross-ministry initiatives.

Challenges and Issues for ODI

- Overcoming inertia and lack of program focus and accountability among the bureaucracy.
- Maintaining links with community groups; managing the logistics of gathering input and providing feedback.
- Overcoming geographic barriers and complexities (i.e. dual diagnosis) associated with service gaps.
- Being able to handle a large volume of calls given ODI's limited resources.
- Setting priorities.
- Encouraging other ministries to free up resources that represent duplicated effort.
- Providing consistent messaging and avoiding confrontation when advocating.
- Forgetting or not losing an Aboriginal focus.

Collaboration Opportunities for ODI and Community Organizations

 Partner with the Premier's Council and other stakeholders on advocacy and other appropriate activities.

Group Red Breakout Session

Community Expectations of ODI Priorities

- Raise awareness of ODI: clarify its role and establish good two-way communications. Answer the question: Where does a person with a disability fit into ODI?
- Take action on referrals and requests:
 - Establish a customer management/tracking system.
 - Ensure accountability ODI and others.
- Assume a 'watchdog' role regarding resource spending:
 - Identify systems and programs that work well.
 - Recognize model programs and systems.
 - Research and analyze disability programs and services seeking efficiencies and savings.
- Facilitate system and organizational relationships and facilitate change where it is needed and where it is possible.

Other expectations

- Be action orientated.
- Act as a collective voice for disability organizations and individuals with disabilities.
- Be an advocate inside and outside government.

- Create more awareness of persons with disabilities in all aspects of life (i.e. education).
- Provide information and educate the construction industry on accessibility needs and standards.

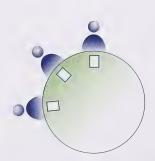
Challenges and Issues for ODI

- Establishing sufficient clout and power to effect change.
- Establishing ODI as accountable, credible and an expert referral source that sets reasonable expectations and performance measures.
- Establishing connections to the nondisabled community and conducting education, promotion and awareness to a degree that changes mind-sets and garners support.
- Providing outreach to those who don't normally self-advocate.
- Getting buy-in from other ministries.
- Overcoming 'turf protection' inside and outside government.
- Identifying economies of scale.
- Encouraging others to share information.
- Preventing a potential backlash from those who prefer the status quo.
- Spreading limited resources too thin taking on too many issues.
- Raising the bar of government programs and services to higher levels of performance.

- Overcoming individual fears that approaching ODI will result in negative ramifications such as funding cuts or problems with service providers.
- Overcoming presumptions from Hutterites, Aboriginals and others that ODI is "not for them".
- Providing on-going communications regarding ODI's actions and processes.
- Providing clarity around ODI's protocol, process and procedures.
- Responding to many organizations and their many different focuses.

Collaboration Opportunities for ODI and Community Organizations

- Stimulate new relationships and knowledge transfer among community stakeholders.
- Strengthen ties inter-provincially and internationally.
- Capture new consumers/clients/ stakeholders for organizations through referrals.
- Develop closer ties with service organizations, health regions, builders, etc.



Premier's Council Panel Comments

with Chair Rob Lougheed and Members Gordon Bullivant and Margaret Conquest

June 18, 2004

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Rob Lougheed

Let me thank you for the comments this morning about the ODI. In our discussion here with respect to the Premier's Council and the future of the Premier's Council, I'll be interested to hear your comments and what you perceive to be the difference between those two bodies – the ODI and the Premier's Council – what successes you perceive that we may have had and what successes you would like to see Council achieve.

I had the privilege of coming onto the Council after it was established for quite some time. There was a review done at the 10-year term about the direction of the Council. They brought in some people, looked at it, checked things out, and decided that a little change in direction would be appropriate. And that's when, as Gary McPherson moved off to the university, the minister of the day that was responsible asked me to move on to the Council as chair. The terms of the Council members are all about to expire and we had all new Council members coming on. At that time there were a few people who made some good comments to me about

the Premier's Council and what it could do.

One of the things I heard was that it had to be more inclusive. And that is it was not to be seen as a Council for say people with mobility issues only, but rather a Council that recognized that there is a broad spectrum of disabilities. And so we had at that time actively looked for Council members who would represent that broad spectrum.

We identified things like mental illness and brain injury that had to be addressed as emerging issues. That influence came from people like some of you in this room who went out and had discussions with people who are your representatives. That stuck with me, and that was part of our initiative. We went out into the community and got some good Council members. They have dwindled in number a little bit over the years, and we are now looking for redefinition and perhaps a rededication of our goals. This conversation will help us to do that. I look forward to your input.

Gordon Bullivant

Years ago Gail Davis and I sat on the working group to establish the Premier's Council. We traveled the province and we listened to issues and problems mostly of parents of children with disabilities. I think there were seven working groups and we came up with the original disability strategy that sat in a closet for ten years. Nothing happened with it.

When we came back on to the Council, a number of us said we're not going to come back onto this Council and do nothing. We're not going to be talking heads for government. We're going to try to make changes and to help the Alberta disability community finally do something.

In all fairness I have to tell you that every Council member felt that way and continues to feel that way under Rob's leadership. We wanted to be action oriented. I think some of the thoughts that will come today will help us and future Council members do that. We haven't come very far. We think we have in very small steps, but we're still coming. Hopefully the ADS will help us push that forward. It already has started.

I was at a meeting only six months ago at the Special Education Advisory Committee for Alberta Learning made up of school superintendents and a number of consumer groups and a number of teachers. Their mission statement – number one – was all children in Alberta will be equal citizens. And number two was all children with special needs will have citizenship. I said stop and asked what is wrong with this statement? They couldn't get it. It took them 10 minutes. It took them 10 minutes to realize that if we're talking about all children, we're talking about all children. And so we eliminated number two. Which was a big step, quite frankly, because they didn't get it. They still had the attitude that special needs kids are an addendum to our education.

We have to be iclusive. If we're talking about all kids, we're talking about all kids, just as we're talking about all Albertans. We have to stop labelling ourselves as being different. I think the issues are exactly the same now as they were when we first started, except now we're action oriented and the government is starting to listen, again under Rob's leadership. So I applaud Rob and the Council for working very, very hard.

There is still one issue that's out there, and it's our own fault as a Council. Many consumers see us as dealing with mobility issues only. It is very important for us to get the message out that we are also dealing with mental health issues and many others that aren't wheelchair bound. We have to continue to push that because the general consumer doesn't know that, and it is our fault that we haven't done that. I would appreciate your remarks.

Margaret Conquest

People ask where do you think the Council is going to go? I am about as curious and mystified as any other delegate today. I think that will come out of yesterday's conversations in relation to how the ODI will look.

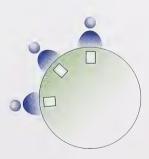
Where do we come from? Six years ago we started with Council. I was very green, and I'm still very green. I was 23. As a Council, we came up with strategies and business plans very similar to the expectations set yesterday and today. We need more new energy, renewed motivation to carry on the momentum. We aren't really in and we aren't really out of government. We've struggled with that public perception and some public relations issues related to that.

Individuals want us to deal with their individual issues and have said you're not much good to us if you can't help. Some organizations view us as part of government and well, why can't you do

anything about AISH? You should be able to. And as Council members we got frustrated along the road with delays and timelines and with the enormous amount of information and the enormous amount of pressure we felt to serve and represent such a broad range of issues.

I think we were delighted, though, to find that we weren't all that special in our individual silos as people with spinal cord injuries or brain injuries or mental health issues.

So those are my broad comments about where we've come from and honestly, I'm not sure exactly where I think we should go. Because just about the time I think I've got an opinion and an idea of where the Premier's Council should go, I talk to somebody else and they tell me that I'm out to lunch. I then back pedal and rethink where I think Council should go. I think the Council should go where you as a group want it to go.



Appendices

From Alberta Disability Strategy to Office for Disability Issues (ODI): Turning Plan into Action

A presentation by Bob Barraclough, Director, Office for Disability Issues

June 17, 2004

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My presentation is more of a technical nature. I'm the bureaucrat, so I get to wander through all the raw technical components of all this. And really what it's about is trying to give you some context as to what we're going to do today, some of the background. I want to speak to where we've been and how did we get here, physically and conceptually with the ODI.

I want to talk about where is here and some details around what this is about. Some of it is a rehashing of what the Minister has already mentioned. But it's in a preplanning kind of context. Then I want to talk about where we're going and how we're going to get there.

To begin with I want to talk a little bit about what happened. How did we get here? How did we get to an ODI? How did we get to make some fundamental changes in the way we approach disability issues?

And it begins with a sense of the landscape. Approximately 1.7 billion

dollars – that's nearly 10% of the provincial budget – is spent on disability supports through 11 ministries. There are roughly 32 programs. Each one of these ministries has a department, a Deputy Minister and a Minister.

We have what's often called the silo effect. Ministers have responsibility and accountability for what their department does. They don't have accountability for what other departments do. A lot of these departments, these ministries, manage and plan within silos. That's just a reality and that's the way things have been.

Because of that there's very limited collective accountability. Very high-level accountability at the cabinet table and the Deputy Minister tables, but fundamentally on the details there is very little accountability. And more importantly, very few mechanisms on which we can draw out that accountability.

It's not necessarily a good thing, not necessarily a bad thing. It's just the way the system works. Let me show you this slide. This comes out of a presentation from the Alberta Brain Injury Network. It is completely incomprehensible but that's the point. This is an attempt to try to graphically display how the system works. It's incomprehensible.

In the middle of that mess of arrows and doors and things is the person with the disability. There's our problem. That's why we're here today. Because of what I call the buzzwords of discontent. We use them all the time. We use them when we talk about these issues. They are used in the ADS.

We talk about fragmentation. Everyone who needs support knows this. We pick it from here, we pick it from there, we pick it from over there, and over time we kind of cobble a network of support around ourselves that gets us through the day. But it's ad hoc. It's incremental and it's fragmented.

What is available and upfront in one Regional Health Authority isn't necessarily available and upfront in another. You have support coordinators here and it's all over the place. There is wide variation in equity. Some groups are getting lots of stuff, other groups aren't getting anything. Part of it relates to the variation in services and programs, part of it relates to the fragmentation.

And there is lack of coordination. There are inconsistencies across the province. It's the way things have evolved and that's why

we're here today. We're also here in the context of the Premier's Council and its experience of working in this environment for a very long period of time.

But we need to understand the Premier's Council was created in a moment. Rick Hanson rolling across the world created some momentum, a moment, and the creation of the Premier's Council was very appropriate for that moment. That moment was in 1985, nearly 20 years ago.

The Premier's Council has evolved. We went from having a full-time chair, someone who spoke on behalf of the community – Gary McPherson. Wonderful man. Did some wonderful work. We now have an MLA chair. I think it was a good change but gave the Premier's Council a different dynamic.

We have a Community Support Systems Division, something that's never been in government before. It has a mandate to deal with disability issues. That's also different. We need to create some different mechanisms to respond to these evolutions. One of the problems we faced and was probably supported by some of the evolutionary changes is that the community saw the Premier's Council as government. The government saw the Premier's Council as community. And so there was an uneasy tension. Now we're trying to create something different.

So where is here? Here is the emergence of the Office for Disability Issues. It's nested within a department. We're definitively in government. What that means is I have a policy and planning team that reports to me. I report to an Assistant Deputy Minister, who reports to a Deputy Minister, who reports to a Minister. And that may seem like a lot of bureaucratic gobbledygook, but for people who are in the system, that's very important. They know who we are, they know our accountability and they know where we're coming from.

What it also does is enable the Premier's Council to be more out. It still has independent, enabling legislation chaired by an MLA. It can do its work on the political side. I can do my work within government. I think we have created a bit more of a rational structure that's understandable for everybody.

The Premier's Council will be supported by the ODI. It's not the same as now. Government people will know that I am one of them. You will know I am from government. And I think we create an environment where there is some understanding around roles and expectations and what we can and cannot do. That's my hope, anyway.

Where are we going? The ADS is where we're going. We've taken a document that was produced by the Premier's Council and I'm going to use it as a framework to guide the actions of the ODI. It now becomes essentially a policy document that can guide our work.

And it will be premised on a framework for full inclusion that is built upon the four key pillars outlined in the ADS: personal supports, financial support, education and employment. It will be buffered by those eight strategic recommendations the Minister spoke about. That's the technical side of what's going to happen.

I want to move to the buzzwords of content and change some of the language. Where we go from fragmentation to cohesion, from variation to consistency, from inequity to equity and to collective accountability. ODI can become that mechanism that will foster the collective accountability that hasn't been there before. We can work through the system and bridge the planning between the silos. We're trying to create that mechanism.

How do we get there? I don't know. But there are 60 some people in this room. I hope you can help me. I see this as being a community initiative. I can drive this a little in government, but we need to build a network around us. It's the only way it's going to happen. We need to come together and decide on the things we can agree on and move those forward as a community, as a network of support around the issue.

We're building momentum. Last week we were in a planning session with the senior management of the department, and one of the people presenting to us first thing in the morning was Julian Nowicki, the senior Deputy Minister in government. He's there to give us a thumbnail sketch of the government of Alberta's 20-year strategic plan. I'm not going to go into all the details of that, but it's essentially four pillars of support driven by 17 strategies.

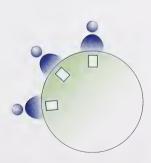
Essentially there are three components to the 20-year plan. At the very outside are 20-year strategic initiatives. On the close inside is the 3-year business planning cycle. In the middle are median term strategic initiatives. There are three of them. One was, not surprisingly, the rural development strategy. Another one was the water strategy, and the third one is the *Alberta Disability Strategy*. I haven't the slightest idea what that means, but it's really good news.

The other week Rob and I met with the CEO of Travel Alberta. The CEO said to us that Travel Alberta agrees there needs to be something done about defining accessibility and bringing it together so people know. We'd like to be a partner in that venture. I'm not sure where that's going, but it's also good news.

People are paying attention, and I think we've got some key momentum. Staffing is underway. Braden Hirst has just joined the office to be my Senior Policy Coordinator. He will be the project lead on a number of these initiatives. Mark Nicoll is currently finishing up a secondment with the Auditor General's Department and he will be joining us on July 5.

You are the first group that we have reached out to. I want to know what you think. We need to do this together. That's the only way we can advance the issues.

Finally, the message I want to leave is about doing things differently and less about doing different things. The Premier's Council has done a lot of really good work and so have the staff. It's about taking that foundation and doing things a bit differently to improve the lives of persons with disabilities. I look forward to the next day and a half.



Inclusion or Illusion?

Keynote Address by Dr. Garry Wheeler, Executive Director Steadward Centre for Personal and Physical Achievement

June 17, 2004

Please note: This presentation was extracted directly from the Symposium transcript. The transcript was produced from real time captioning and not an audiotape. It is not certified therefore as a verbatim record. This material has not been edited for content, grammar or syntax.

Ladies and gentlemen, and distinguished guests, thank you for inviting me to come and speak with you this evening. The title of the talk is Inclusion or Illusion, and it speaks to a conference that I ran some time ago with the help of Bob and others in the room. And we did indeed look at the issue of inclusion. It comes from the concept of assumptions. Let me give you an example of an assumption.

As a psychologist, which is my other hat that I wear temporarily but not very often, I deal with anger management. Not the Jack Nicholson kind, but I dealing with anger management involving people with brain injury who have lost a great deal. And I have learned a lot about what it is to lose some of those things that we hold dear to us, such as abilities. I remember going up to a ward and a young woman – a quadriplegic – said, "Doc, come here." She grabbed me by the tie, pulled me down and gave me a big kiss. She said, "Doc, remember I'm injured from the neck down, not the neck up."

This is key because it's about the concept of assumptions. She was making the notion of the concept of spread. In other words she assumed that I would assume because of physical disability intellectually

there was something wrong as well.
Assumptions are really the root cause of why we've got to the inclusion movement.
Marcia Kinsella referred to assumptions that are very negative and a fundamental negative bias towards disability.

For example, spread: Assuming someone with vision impairment is deaf. Secondly, the outside perspective: "We know what's good for you." Paternalism. Thirdly, distress identification: "If that were me, that would be awful". How many times have we heard that? I hear that all the time. Someone with a disability comes into my local pub. I have a local pub in Millwoods, and we have some folks who come there who use wheelchairs, and always the discussion stops and you can see the thinking, if you understand what I mean.

Sometimes people's disability is subject to what we call the assumptions of ablism, which are described by Davis as having three underlying assumptions: that persons with disabilities are tragic victims, that they are dependent and that they are in need. Moreover, disabilities are a biological phenomenon that becomes individual and is correctible through remediation. What Cavallucci calls the fix

them approach. So what are the results of this? Well, clearly stigmatization of disability. So there is a tacit acceptance but not a real inclusion. In other words, people are included but socially excluded. The individual is in a state of limbo, social undefined, floating somewhere between sickness and health.

So these negative assumptions have clearly driven the movement to inclusion over the years, but it's a long history and it's worthwhile talking about it. I invited Marty Block to be the keynote speaker at the Inclusion to Illusion conference in 2004 in the spring. A long-time total inclusionist himself - in other words, there is no option – he commented: "Inclusion is perhaps the most feared and emotionally charged educational reform since the passage of public law 94.42, which was legislation in the states which for the first time said you have to provide educational opportunities for children, and, moreover, you have to give them access to physical education."

Whether in formal debate or informal gatherings, in teachers' lounges nothing can divide a room of educators like discussions of inclusion. And basically what he was referring to was a rather moralistic focus on simply placing kids in classes without thinking about what their needs were. So what was the issue 10 years ago? Well, it was about placement and not focus on need.

There was a failure to recognize that children had needs above and beyond the needs of children who were able to move around quite easily. They had other things that were needed. Unfortunately, it was used as a reason for abdicating

responsibility for funding, and inclusion became a very cheap way of losing some staff members. And that's exactly what happened south of the border. Moreover, the children were included in classrooms in name only, in concept only, and often reported being socially isolated. So that's where we were.

So my inspiration then a few years ago was to write a talk called Inclusion or Illusion? I asked the question, what is inclusion? If we know what it is, is it working? And if not, why not? And if it is, how is it working? And a few years later, still not satisfied of the answer, we had 300 people that got together at the university and started to debate that question in the early spring, in April/May of this year. And we asked some very fundamental questions of them. I simply asked them, come and talk to us about inclusion. What about it? I said it doesn't matter. Come and talk about it from your perspective.

Now, it's important, I think, to recognize that to get to that point where we could actually even think about what inclusion is, we have to look at where the roots of inclusion come from. We can look at attitudes towards disability, because core assumptions are rooted in attitudes, which are rooted in beliefs.

There has been three or four major paradigms historically that have really dictated the fate of persons with disabilities. A religious model that conferred the notion of some magical, mysterious, even demonic notion of disablement. A psychiatric disorder in England in the middle ages would get you a date with the stake. It meant possession.

It was about abandonment, infanticide, and persecution in the dark ages.

Medical paradigm. The renaissance period was focused on knowledge and the development of medicine, and we began to classify persons with disabilities with having this or that, and therefore we could do this or that to them to make them better. This started resulting in things such as institutionalization of individuals with disability.

And then the rights-based advocacy movement, arguably a child of the post second World War period, when we started to say this could never happen again. Didn't learn much, did we? Then basically we began to recognize, with the visibility of disability particularly in Europe, that something had to be done. And therefore the rights-based movement was born, and their more familiar terms of normalization, mainstreaming, integration and then inclusion have basically come up through a corrections model, a supports model, a services model, and now a personal empowerment model.

So that's the history. That's where we are today. You can almost think of it like an upside-down curve. Those are the progressions of attitudinal periods that we have gone through. We're now at the inclusion component apparently, whatever that means.

So where to from here? Do we go up, or is there a danger of going down? I will revisit that in a moment. It's been suggested that all of these paradigms continue to confer differences within an inclusive paradigm. The advocacy movement, for example. People are seen as needy, dependent, requiring assistance.

And some people would argue they want to lose that label, without caution. Inclusion would not have the same negativity.

So for two days we listened to some academics, community folk, people who run organizations. And two major themes came out of the conference with regard to the concept of inclusion. They were the good, the bad and the ugly. Much aligned with school. The other theme was about inclusion and community. Community was a keyword that arose again and again.

So is inclusion a good thing or bad thing? We had a number of speakers who spoke to this, and mainly in the area of school programs. Essentially it was determined that it is important in schools, and it is a good thing in community. But there are also some side issues that are important.

The good was that inclusion does work. In classrooms where teachers who are well prepared, have good attitudes with adequate support and services, children do quite well in inclusive classrooms. But not always was the key. Marty Block pointed out that there are still problems, and they are all based on false assumptions today, particularly south of the border.

It assumes that teachers have positive attitudes towards kids with disabilities. Not everyone does. They don't understand it. Positive attitudes among administrators? Not always. Recognition of abilities rather than disabilities? Not always. Staff trained and ready to deal with it? Not always. There is this notion that somehow simply placing children with disabilities in the classroom equals inclusion. Into the class you go, you are now included. That still is a problem today.

The ugly came out as Marty Block quoted from some students who shared their experiences of being included in regular education. In one case, an instructor told the student to leave because they were a liability. In another they sat in the library for an hour every day, while the rest of the class got phys ed. And the nonsense of that is clear. Marty concluded that this is interesting. Full inclusionists in the past have said to even discuss it in public is a problem. You are immoral to even study it because you may disprove the null hypothesis. It is an inalienable right and it should not be discussed.

It is here. We know what it means. Or do we? Well, Marty used to feel that way. He now says let's stop beating ourselves up trying to put kids with disabilities in a setting because we think it might be morally correct to include them when that setting is weak for any kid.

Dick Sobsey took a different view. He said you are talking about the right to inclusion. He said that it's the right not to be excluded that we need to talk about. Sobsey says once we develop systems to segregate or isolate people who present social accommodation problems, we open the door to the treacherous legitimization of excluding people whose behaviour make us uncomfortable. Yet he too noted, like Block, that secondary choices may be important, and we lose some things when we start to dilute the culture around disability.

Much like deaf culture. Donna Goodwin ascribed to that. Donna is also an inclusionist. She believes that the best thing is for all kids to be together in the community and in schools. But she concluded, having studied the experience

of children in segregated or special camps, that ideologically, financially and emotionally supporting the inclusion of persons with disabilities in programs originally designed for persons without disabilities causes issues of isolation, loneliness and disempowerment to surface.

And she described summer camps for kids with disabilities as therapeutic landscapes. Therapeutic landscapes where kids learn to socialize with kids who experience the world the way they do. The kids have their own unique lived experiences, and perhaps they understand when others don't. In other words a refuge from the assumptions of ablism as she described it. She talked about wheelchair dance and asked children to describe their experiences. They said it was a dream come true. They felt like there were with kids who could relate.

This is not exclusion. It's specialization. It's the kind of thing that we do at the Steadward Centre. And for years we have often said we are a segregated environment. No we're not. We're a specialized environment. If people want to go downstairs, they can, but often people say no. I don't like wearing a label around my neck. I'm quite happy here because people understand what I need. So it's not the right to be included. It's the right not to be excluded. And it's the right to be able to make the choice.

It seems people have come full circle somewhat in their view of inclusion. Having a focus on placement versus need was a big problem. I hate the word placement. Placement does not equal inclusion. Placement may in fact lead to isolation. The right to choice is important, and alternatives may provide therapeutic

landscapes, to be free from ablistic assumptions. The good, the bad and the ugly.

The second thing discussed at the conference was inclusion in community. It was dominant throughout. And it followed a sequence. The themes arising were issues of isolation in communities. Tom Fowler spoke about that. Social contact and interactions were important if we're going to have inclusion. People have to interact, quoting Sherrill. Placement does not mean inclusion. Many people said that. Respecting and acknowledging gifts was the way in which attitudes will change, when people are seen as an asset, not a liability.

The importance of developing capacity came up again and again, capacity for inclusion. That's the human capacity for inclusion. Access is fine for infrastructure and for services. But what about access to our sensibilities? That's what it's about. Removing barriers like poverty and attitudes. Strategies for inclusion came up, and obviously that includes the ODI, the *Alberta Disability Strategy*, and so on. And Bill 201.

When we talk about this in context, I'm using a very generic term to define disability because in fact if we look what disability is now, it's actually defined in the classification of functioning. An impairment of function and environmental factors combine to limit participation in activities. This is what defines disability. In other words an interaction with your environment – say community – and impairment of function, that's what confers disablement.

In other words an inclusive community does not have persons with disability. People are in the community but not part of the community if they are socially isolated. Gary MacPherson said that people with disabilities have traditionally been in the advocacy model because of the focus on governments, on money and fiscal agendas to alleviate social and economic isolation.

And Tom Fowler talked about the same thing. In the Alberta brain injury studies one of the most important things people talked about is feeling socially isolated. Simply being in community is not enough. As Donna Goodwin says people with disability are commonly noticed by everyone and acknowledged by nobody. And what does acknowledgement mean? There is a value statement in that. Sherrill said I have come to the conclusion that inclusion is made up of hundreds of thousands of meaningful social interactions, not a "Hi, how are you?"

I remember once picking up a fellow at the airport who worked with Bill Clinton. He had a visual impairment and he had a guide dog. We're driving out of the airport and his dog insisted on standing right on the front of the dash and looking out the window. As I paid for my parking, the lady looked in and said, "Oh, he's lovely. What kind is he?" And the fellow said, "I'm an American."

Paternalistic recognition of people is not what it's about. It's about meaningful social interaction. Placement is important. Physical access is important and recognition is important and interaction is important, but it's not enough. Perhaps

inclusion is when we recognize people as having gifts and assets. Gary referred to this. He said maybe what we have to do is use a marketing analysis to talk about disability, so that the disabled community is seen as a market. It is an economy. Maybe then we're talking the same language with those who would set fiscal agendas.

Mike Green gave a workshop on assetbased community development. And he said when communities want to move forward together it's critical not to look to the outside and say give me but look to the inside and say what can we do for ourselves. Who do we have? What gifts and assets do we have? And that is everybody. His message to us was that's the challenge of disability. So placement, social interaction and recognition of gifts get us closer towards a decent definition. And perhaps recognition.

When people talk about disability sport, that it's not something separate from sport. It's an entity, and it's something where people can celebrate their successes. It's not a way of just offloading people with disability into another environment. People make choices to be there. It's certainly about celebrating victories that everybody can have.

A study I conducted years ago typifies how people don't feel isolated when they feel they have identity. An athlete said, "When we are on the track, I think we don't look at ourselves as disabled. When we're in our racing chair, it is like putting on a uniform. You are out of it now. You are out of the disability. It's like putting on a superman vest. Not normal, but supernormal." To

say that doesn't confer some advantage or benefit would seem foolish, wouldn't it?

So clearly inclusion is about being in community, about being part of community, about interacting with people, about being recognized for the gifts you have, not as some liability or someone needy, but someone who has ability and is independent. And it's also about realizing that we have a right to choice. And I say we because I have a disability. I'm blind in one eye. I have chronic degenerative arthritis. I like to have choices.

Poverty and attitudes were seen as big barriers to disability. In terms of poverty and attitudes, Clark Sloan talked about employment. Being employed is being part of a community. But people with disabilities are unemployed, underemployed, and it gets worse as severity of disability goes up. And he talked about housing. One of the most important things about inclusion is having a home. How can you have a home if you don't have money, don't have a job, if there isn't enough housing.

You should have the freedom to be integrated. It's okay to use the word integration because integration is being in the community. Feeling included is what it's about. It's about being integrated to the point of feeling included. Maybe that's a description. It allows you to establish intimate relationships, raise a family and have privacy. But even this can come with disincentives.

I remember a number of years ago writing a piece with Neil Pierce about compensation inhibition. We talked about claw back processes for things like AISH, CPP and child benefits. What these claw backs do are scare people into staying dependent. People are frightened of going off of benefits. We termed it compensation inhibition. There is a term in the literature called compensation neurosis. If you have an injury and you are in litigation, you play the part even to the point where you come to believe that you have a disability. The notion being that often people suddenly get better after compensation.

Obviously that's not a very popular opinion. I argue it is not irrational. It is a rational decision not to work for fear of loss of benefits. So clearly part of being included is being able to take a risk, being allowed to risk, having the right to risk. Why shouldn't a person with a disability climb Everest? It is a big mountain to climb when you can't take the first step.

Disability discrimination is a barrier to inclusion. How can we get positive attitudes towards disability when we fight amongst ourselves? I remember when I went to the world championships in Berlin involving wheelchair sport. It was the first time persons with intellectual disability were included in the games. I was the one tasked to go and ask athletes who use wheelchairs what they thought about this, but in a very roundabout way. It was called blind research. It didn't take people two seconds to know what I was asking about. I won't repeat what they said. I was shocked at the disability discrimination at that time, even among athletes. Hopefully it's not as bad now.

So what have we heard? Inclusion has something to do with a right not to be excluded, a right to choose, removal of barriers, appreciation of a culture, appreciation of gifts, and facilitating change in attitude through that appreciation of gifts. And perhaps access - access to services, access to support. Tom Fowler talked about 11 ministries, one door. Perhaps a challenge for ODI is to help bring that to fruition.

As I said before, when we talk about access, it's often thought of as physical access. I think we need to talk about access to sensibilities and sensitivities. And perhaps through community and assetbased community development we might do that. So what initiatives are there? Bill 201, the Alberta Disability Strategy, the Office for Disability Issues, the Alberta brain injury initiatives, Spinal Cord Injury Collaboration Initiative, and the assetbased community development trend. All of these are addressing many of those issues. Access, for example, is addressed specifically in Bill 201 and the Alberta Disability Strategy.

But a note of caution on community. The caution comes from Dick Sobsey who said he came back from New Zealand to Edmonton and I arrived thinking there had been a nuclear war. Nobody was around. Everybody stayed indoors. Do we really have communities any more? Or is technology like cyber interaction reducing the need for human contact? I would argue that e-mail is the death of the English language. But it also a perfect reason not to communicate with people face to face.

Russell Carr asked a very critical question. He said in 2005 we're going to metaphorically burn the mortgage. We will be amid a sea of wealth in this province.

The one discussion I don't hear beyond fiscal agenda, outside of the ODI and Bill 201, is what kind of community do we want? He said, "I don't hear any talk about that." Maybe the best thing we can do is become a model for developing inclusive communities. It's one of the great things we can do to move forward.

In conclusion, have we made progress? Are we continuing to make progress? Clearly we are. I don't think there is any doubt about that. Let me leave you with the words of Cavallucci. He said: "Inclusion is a concept more than just integration. It's meaning must reach deeper into community life. Inclusion must convey a sense of belonging. Too often persons with disabilities are in their surroundings but not an integral part of them. Inclusion means being at the table, being part of the discourse, being respected for who you are. Not held accountable by the assumptions of ablism, what others might expect you to do. It acknowledges that people may be different."

So eliminating difference may not be the way to go. It pushes us to respect diversity. It's a term that implies welcoming to all. What if we do eliminate difference? Imagine if we eliminate difference. We see people as not different for others, having no special requirements, an anonymity of disability. Much like compensation inhibition. If we decrease the need for advocacy, do we end up abandoning people? So advocacy is still required clearly. We need to advocate for inclusive communities. So let us set the bar high in relation to that and hold ODI to do some good work there.

Let me just finish with what one of our graduate students wrote. We asked them to sit through the conference, and I said I want you to report and summarize what you heard. And Nancy Cavalier and her colleague went away, and they said the one thing above all was that came forward was that people are social beings within the community, in relationships with each other. And she asked if it was okay if she used a metaphor to describe inclusion. Her metaphor was this: "Perhaps it was love at first sight or maybe it just grew on me, or maybe after enough persistence you agreed to go out on a date. That first date was good. You agreed to another. Or maybe it was dreadful and you never went out on another again." The point is there can be good and bad times in relationships. A relationship can give you opportunity to be more than you thought you were or could be, help you and others to see that you had something to contribute. Or maybe it just reaffirmed what you already knew about yourself all along.

Relationships can be bad. They can be controlling, involve severe dependence and remove choice. Along with dependence may come the loss of self and a perception that you are somehow less. It can mean the loss of your own voice and value. Relationships are hard work, and there are profound reasons why we continue to seek them out, engage and reengage in them. Relationships change, grow and evolve. The ideas that people have also change, grow and evolve. And certainly inclusion is one of those ideas.

Premier's Council on the Status of Persons with Disabilities

Disability Community Symposium

Red Deer, Alberta • June 17 & 18, 2004

Agenda

Day 1 – June 17

1900 – 1000 Registration & continental breakfast

1000 – 1100 Welcome: Rob Lougheed, Chair, Premier's Council on the Status of Persons with Disabilities.

Opening Address:

Honourable Gene Zwozdesky, Minister of Community Development

Special Presentation: City of Red Deer

1100 – 1200 From Alberta Disability
Strategy to Office for
Disability Issues (ODI):

Turning plan into action:
Bob Barraclough, Director,
Office for Disability Issues
Question & Answer session
Instructions for afternoon
small group work

1200 – 1330 *Lunch break*

1330 – 1600 Small group work:

 Brainstorm community expectations of ODI. Prioritize expectations.

- 2. Identify challenges and issues associated with ODI trying to meet community expectations.
- Brainstorm collaboration opportunities between ODI and community organizations.

Please note: Refreshments will be available in the small group breakout rooms.

1600 – 1615 Plenary: Day 1 wrap-up.

1800 – 1900 Reception hosted by Rob Lougheed and members of the Premier's Council.

1900 – 2100 *Dinner*

Premier's Council Awards of Excellence Update:
Rob Lougheed

Keynote Address:
Dr. Garry Wheeler,
Executive Director,
Steadward Centre for Personal
and Physical Achievement

Day 2 - June 18

0800 – 0900 Continental breakfast

0900 – 0945 Plenary: Report of small group findings from previous

afternoon.

0945 – 1045 The Future Role of the
Premier's Council: Open
discussion with panel
composed of Premier's
Council Chair Rob Lougheed
and Council members Gordon
Bullivant and Margaret
Conquest.

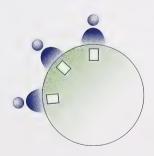
1045 – 1100 Refreshment break

1100 – 1200 Evaluation & suggestions:

- Disability Community Symposium
- International Day for the Disabled activities

Closing remarks:Bev Matthiessen,
Alberta Disability Forum.

1200 - 0130 Lunch



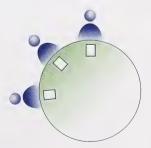
List of participants

- Deanna Kirk, Accessible Housing Society of Calgary
- Robyn Jackson, Accessible Housing Society of Calgary
- Norm McLeod, Alberta Association for Community Living
- Lori Adamchick, Alberta Association for Community Living
- Tracie Matthiessen, Alberta Committee of Citizens with Disabilities
- **Bev Matthiessen**, Alberta Committee of Citizens with Disabilities
- Cathy Kruger, Alberta Association of the Deaf
- **Don McCarthy**, Alberta Association of the Deaf
- Gail Davis, Alberta Association of Rehabilitation Centres
- Maureen Murphy-Black, Alberta Association of Rehabilitation Centres
- **Dr. Doreen Sturla-Scott**, Alberta Council on Aging
- Dawn Blaeser, Alberta Easter Seals March of Dimes
- Karen Phillips, Autism Society of Alberta
- Lynne Romano, Brain Injury Association of Alberta
- Shelly Weiser, Brain Injury Association of Alberta
- Clarence Littmann, Canadian Council of the Blind

- Brian McIvor, Canadian Council of the Blind
- Peter Portlock, Canadian Mental Health Association
- Jo-Ann Dumont, Canadian Paraplegic Association
- Larry Pempeit, Canadian Paraplegic Association
- Marlin Styner, Canadian Paraplegic Association
- Laurie Keban, Catholic Social Services
- Barbara Humphries, Catholic Social Services
- Mezaun Lakha-Enh, Cerebral Palsy Association of Alberta
- Janice Bushfield, Cerebral Palsy Association of Alberta
- Trevor Crick, Chrysalis
- Gerald Hanowski, Chrysalis
- Helena Lake, CNIB
- Colleen Robinson, Connect Society
- Nori Majeau, Connect Society
- Iris Saunders, EmployAbilities
- Ed Lavallee, EmployAbilities
- Sue Carstensen, Friends of Children with Special Needs
- Bernie Leins, Goodwill Industries
- Stacey Carmichael, Handicapped Housing Society of Alberta
- Wayde Lever, Handicapped Housing Society of Alberta

- Marilyn Jewell, Leadership Centre
- Harvey Finnestad, Learning Disabilities Association of Alberta
- Lorrie Goegan, Learning Disabilities Association of Alberta
- Austin Mardon, Mental Health Self Help Network
- Carmela Hutchinson, Mental Health Self Help Network
- Carol Carifelle-Brzezicki, Metis Settlements General Council
- Yvette L'Hrondelle, Metis Settlements General Council
- Bill Tillier, Muscular Dystrophy Canada
- Jill Gerke, Muscular Dystrophy Canada
- Teren Clarke, Muscular Dystrophy Canada
- Jim Haiste, Parkinson's Society of Alberta
- Barbara Stewart, Persons with Developmental Disabilities
- Garry Donald, Persons with Developmental Disabilities
- Joyce First Rider, Red Crow College
- Irv Zemrau, Schizophrenia Society of Alberta
- **Jim Adamson**, Schizophrenia Society of Alberta
- Ellen Kemp, Seniors Advisory Council for Alberta

- **Denis Cooney**, Southern Alberta Brain Injury Society
- **Donna Bulger**, Spina Bifida and Hydrocephalus Association
- Beth Kidd, The Arthritis Society
- **Genevieve Fox**, Treaty 7 First Nations of Alberta
- Roxanne Ulanicki, Spina Bifida and Hydrocephalus Association
- Ewen Nelson, Steadward Centre for Personal and Physical Achievement
- Gerald Gordey, Premier's Council
- Shirley Dupmeier, Premier's Council
- Carrielynn Lamouche, Premier's Council
- Gordon Bullivant, Premier's Council
- Margaret Conquest, Premier's Council
- Judy Hellevang, Premier's Council
- Linette Kelly, Premier's Council
- Rob Lougheed, Premier's Council



Premier's Council Members

The current Premier's Council is composed of nine members. Rob Lougheed, MLA, is the current chair of the Premier's Council. Premier's Council members represent a broad background of cross-disability knowledge and a diversity of geographic locations in Alberta.

Rob Lougheed, Council Chair

Rob Lougheed is the Premier's Council Chairman and has spent most of his life in the field of education. The MLA for Clover Bar/Fort Saskatchewan has over 28 years of experience as an Alberta educator. In addition to being an MLA and his position as Chair, Rob currently serves as a member of the following committees: Standing Policy Committee on Learning & Employment, Capital Region Caucus, the Select Standing Committee on Public Accounts, the Farm Property Assessment Review Committee, and the Alberta Heritage Savings Trust Fund Standing Committee.

Gordon Bullivant

Gordon Bullivant of Calgary was the Chair of the Education and Learning Supports Committee and a member of the Full Citizenship Committee for the development of the Alberta Disability Strategy. He is the Past President of the Learning Disabilities Association of Canada and continues as the Chair of the National Legal Committee and member of the Professional Advisory Committee. He is an active member of the Calgary Stakeholders Group for Learning Disabilities and represents the Premier's Council on the Advisory Committee for Alberta Learning's Review of Special Education.

Gordon is the Executive Director of the Foothills Academy, a centre for children with learning disabilities. It is recognized internationally for its expertise in teaching techniques, research and practical application of program needs to children and youth with learning disabilities and/or Attention Deficit Disorder. Gordon has been active in the special needs community for over 30 years.

Shirley Dupmeier

Shirley Dupmeier of Medicine Hat was a member of the Financial Committee and the Personal Supports Committee for the development of the *Alberta Disability Strategy*. She has extensive experience working with issues surrounding visual impairment and other disabilities and is a liaison with many disability organizations in Medicine Hat.

Gerald Gordey

Gerald Gordey, formerly of Vegreville and now residing in Edmonton, was the Chair of the Alberta Disability Strategy's Financial Supports Committee. He has a long history of community involvement and has contributed to many disability organizations as an advisor or volunteer. Gerald has been a County Councillor, School Board Chair, representative of the Vegreville Health Unit Board, and advisory member of a voluntary hospital board. He has served on the Board of Directors for Edmonton Social Services for the Disabled, Alberta Rehabilitation Council for the Disabled, Alberta Special Olympics, and the Handicapped Hunter Review Committee. He is also the former chair of the Vegreville Association for Living in Dignity (VALID), a volunteer organization responsible for providing services to persons with disabilities in the Vegreville region.

Judy Hellevang

Judy Hellevang of Calgary was a member of the Full Citizenship Committee and the Education and Learning Supports
Committee for the development of the Alberta Disability Strategy. As a volunteer, Judy has been associated with the Developmental Disabilities Resource Centre (DDRC) of Calgary for 19 years. She facilitates the DDRC's Board Advisory Committee, which is made up of people with developmental disabilities. Judy has been an advocate for many people with disabilities and continues to promote their rights.

Jim Killick

Jim Killick of Morinville was Chair of the Coordinating Committee for the *Alberta Disability Strategy*, as well as Chair of the Personal Supports Committee and member of the Employment Supports Committee. Jim has been actively involved in the field of community rehabilitation in the province for approximately 20 years in the areas of counselling, program development and administration. He is presently working with the Canadian Paraplegic Association and continues to be involved as a participant in numerous community associations working towards removing the barriers facing persons with disabilities.

Carrielynn Lamouche

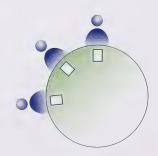
Carrielynn Lamouche is a Metis consultant from Gift Lake, one of Alberta's eight Metis settlements. She possesses a degree from the Royal Conservatory of Music and a Masters degree in Social Work. An Aboriginal person with disabilities, she works with governments in the area of social programming. She also assists governments, businesses and educational institutions to identify and remove barriers that prevent or discourage persons with disabilities from full participation in the community. Among her extensive committee work is service on the Aboriginal Healing Foundation Board, the Provincial Human Rights Multicultural Education Fund Advisory Committee and the Canadian Institute of Health Research Ethics Standing Committee.

Margaret Conquest

Margaret Conquest of Edmonton was the Chair of the Employment Committee and a member of the Personal Supports
Committee for the development of the Alberta Disability Strategy. Margaret has a Masters of Science in the Health
Promotion Program at the University of Alberta. She studied the impact of acquired disability and rehabilitation services on the sexual health of women with spinal cord injuries and continues to chair or present at National and Provincial Conferences. She is actively involved in therapeutic recreation programs and health promotion for persons with disabilities.

Linette Kelly

Linette Kelly of Calgary is a public representative on the Students Finance Appeal Committee and past director of Project 118 Children Services Society. She has served on many volunteer committees as a fund-raiser, including an annual benefit for the Calgary Homeless Foundation. She has been an advocate for persons with developmental disabilities for many years and is an active caregiver for a sibling who has a developmental disability. Linette is an executive assistant and corporate secretary for a Calgary consulting firm.



ODI Press Release

February 20, 2004

New disabilities office to provide better coordination, improved access, increased awareness

Edmonton... The new Office for Disability Issues, announced in this week's throne speech, will allow government to better coordinate policies and programs. As a central place to discuss disability issues, provincial government departments and stakeholders will have the opportunity to collaborate on and strengthen long-term planning to address the needs of Albertans with disabilities.

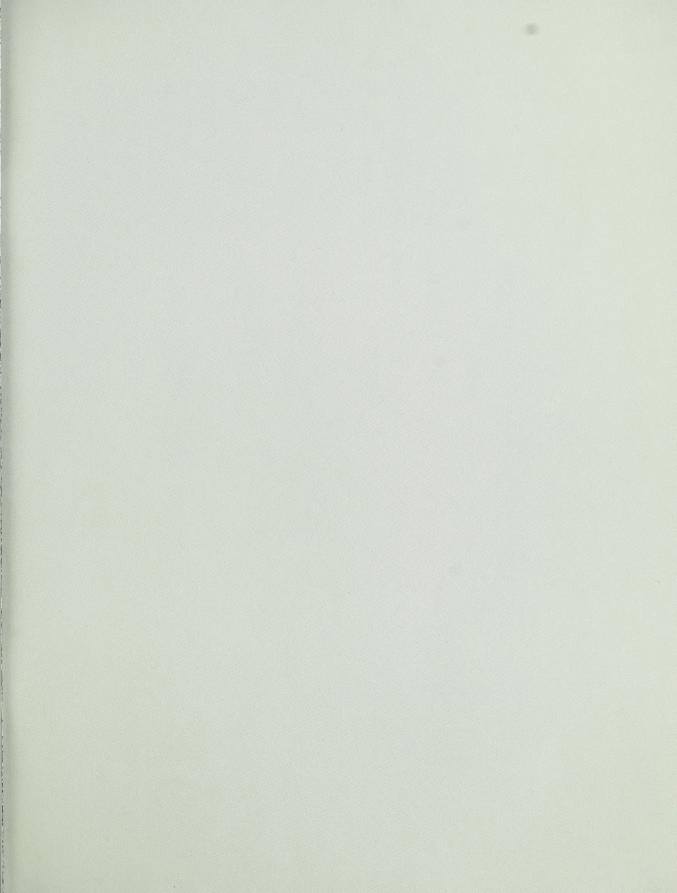
The Office for Disability Issues will assist government in responding to the *Alberta Disability Strategy*, released by the Premier's Council on the Status of Persons with Disabilities in December 2002, by creating a mechanism for stakeholders and various government departments to work together to address the recommendations within the strategy. The overarching change recommended by the strategy is for government to take a more holistic approach to addressing disability issues.

"This Office will provide stronger coordination of programs and policies for Albertans with disabilities," said Minister of Community Development Gene Zwozdesky, responsible for the Persons with Developmental Disabilities (PDD) program and the Premier's Council on the Status of Persons with Disabilities.

"The Premier's Council on the Status of Persons with Disabilities will take on the added responsibility of being an advisory body to the Office for Disability Issues, providing advice and guidance," added Zwozdesky. Specifically, the Office for Disability Issues will:

- provide a reference point for enquiries concerning matters affecting persons with disabilities;
- improve communication with the community to identify issues affecting person with disabilities;
- assist with the development and implementation of policies across government departments to remove barriers and create accessible programs and services;
- promote positive attitudes and raise awareness of disability issues;
- assist with efforts to ensure that the concerns and issues affecting Albertans with disabilities are represented in federal/provincial/territorial processes;
- evaluate the status of Albertans with disabilities; and
- promote additional accountability of government programs.

The Office for Disability Issues will be housed in Alberta Community Development, with administrative logistics worked out over the next couple of months. Albertans who wish to discuss disability issues may contact the new Office for Disability Issues at (780) 422-1095 (or toll-free at 1-800-272-8841).







Phone: 780-422-1095 (Voice or TDD)

Email: pcspd@gov.ab.ca